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ABSTRACT

This policy research brief summarizes findings of a multistate assessment of postschool outcomes and community adjustment for young adults with severe disabilities, the National Transition Study of Individuals with Severe Disabilities Leaving School. The study was intended to provide policy-relevant information on the postschool outcomes and community adjustment of this population and document the difficulties these individuals encounter in accessing community services. The study sample consisted of 398 young adults with severe disabilities across five states (Colorado, Illinois, Massachusetts, Minnesota, and Texas). The subjects had been out of high school from 1 to 4 years. Data collection instruments included a 100-item post-school outcome survey and the Inventory for Client and Agency Planning. Results are reported for the following nine outcome domains: (1) school experiences/completion, (2) employment and daytime activities, (3) living arrangements, (4) family and friends, (5) community involvement, (6) financial independence, (7) personal choice, (8) family needs and support, and (9) waiting for services. Overall, findings illustrated a pattern of limited access to postsecondary education programs, employment instability, dependence on others for residence and other forms of support, limited participation in community social events, and significant levels of social isolation among these young adults. (Contains 27 references and lists 13 related publications.) (DB)

UNIVERSITY OF MINNESOTA

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Policy Research Brief

CENTER ON RESIDENTIAL SERVICES AND COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Postschool Outcomes and Community Adjustment of Young Adults with Severe Disabilities

This Policy Research Brief summarizes selected findings of a multi-state assessment of postschool outcomes and community adjustment for young adults with severe disabilities. The study, entitled National Transition Study of Individuals with Severe Disabilities Leaving School (NTSSD), was conducted by the Institute on Community Integration at the University of Minnesota, in cooperation with the University of Vermont and the University of Illinois at Urbana-Champaign. Authors of this issue are David R. Johnson, Kevin McGrew, Laura Bloomberg, Robert H. Bruininks, and Hung-Chih Lin of the University of Minnesota. The research was funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research, Grant #H133A10010.

■ Introduction

The transition of youth with severe disabilities from school to work and community living continues to be a major concern among parents, professionals, and policymakers. Ongoing attention to the transition years has been maintained since the mid-1980s due to widespread reports of limited outcomes achieved by young adults with disabilities as they leave school and attempt to access employment and adult community services. While postschool adjustment difficulties are experienced by youth with disabilities in general, individuals with severe disabilities encounter a number of special challenges. These young adults often require multiple services from community agencies to successfully access and participate in postsecondary education, employment, community living, and other aspects of adult life. Inadequate high school preparation, ineffective interagency planning, and limited access to adult community services and essential family supports are often cited as problems associated with postschool adjustment difficulties.

Special education services in the United States have experienced substantial growth since the inception of the Education for All Handicapped Children Act, Public Law 94-142, in 1975. During the 1992-93 school year, 5,170,242 children from birth through age 21 received special education and related services under the Part B and Chapter 1 State Operated Programs (SOP) – 3.7% more than were served in 1991-92 (U.S. Department of Education, 1994). Despite declines in the nation's general education enrollment during the 1970s and 80s, consistent increases in the number of children and youth with disabilities served in special education programs occurred over this same time period. Approximately 6.4% of all children from birth through age 21 in the resident population were served under Part B and Chapter 1 (SOP) special education programs in 1992-93, compared with 4.5% in 1976-77. The total special education population in the United States has increased 23.5% since the inception of the program in 1976.

One of the most dramatic influences of mandated public education for children and youth with disabilities has been the increase in the total number of 18-21 year olds served over the past two decades. Young people between the ages of 18 and 21 served in public school programs are generally those with more "substantial" levels of disability, who require extended educational services. In 1978-79, 102,173 students aged 18-21 were served under Part B, but in 1992-93, the number had risen to 210,460, an increase of 106% (U.S. Department of Education, 1994). As the number of students with severe disabilities exiting the educational

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system continues to rise, there will be increased demand and competition for already scarce resources and services in communities nationwide.

Much of what we understand today regarding the needs, status, and community adjustment of young adults with severe disabilities has evolved from previous follow-up and follow-along studies. The vast majority of these studies have focused on the postschool adjustment of former special education students with mild disabilities (Edgar, 1987; Fardig, Algozzine, Schwartz, Hensel, & Westling, 1985; Halpern & Benz, 1987; Mithaug, Horiuchi, & Fanning, 1985; and others). Recent studies on the post-school status of students with severe disabilities (Edgar & Levine, 1986; Edgar, Levine, Levine, & Dubey, 1988; Haring & Lovett, 1990; Hasazi, Gordon, & Roe, 1985; Sitlington, Frank, & Carson, 1991; Thurlow, Bruininks, & Lange, 1989; Thurlow, Bruininks, Wolman, & Steffens, 1989; Wehman, Kregel, & Seyfarth, 1985) provide a number of insights regarding the postschool status and community adjustment of young people with severe disabilities. For example, these studies have found that:

- Relatively few individuals with severe disabilities work competitively in the community. The community-based employment rates vary between 0% and 20% across studies. The more common employment outcome for young adults with severe disabilities is to work in a sheltered workshop or day activity program (52%-77% across study samples).
- Earnings among individuals with severe disabilities are low. Young adults with severe disabilities earn, on average, $150 or less per month and less than one-fourth receive fringe benefits.
- While 50%-60% of non-disabled young adults participate in some form of postsecondary education, less than 10% of individuals with severe disabilities participate in these programs.
- The most frequently documented living arrangements for young adults (ages 18-25 years) with severe disabilities include 50%-70% in residential placements (group home) and 30%-45% living with parents.
- Following exit from school, many young people with severe disabilities become socially isolated and minimally participate in recreation and leisure activities outside the home. Recreation and leisure activities most frequently found across studies among these young adults include watching television, listening to the radio, and sitting around resting.
- Several aspects of citizenship and community participation have been examined in several postschool outcome studies. These studies reveal that few individuals with severe disabilities are registered voters, manage their own finances, or pay taxes.

■ Purpose and Method of Study

The purposes of the National Study of Individuals with Severe Disabilities Leaving School (NTSSD) were (1) to provide policy-relevant information on the postschool outcomes and community adjustment of young adults with severe disabilities, and (2) to document the difficulties these individuals encounter while accessing community services. The study sample consisted of 398 young adults with severe disabilities from across five states (Colorado, Illinois, Massachusetts, Minnesota, and Texas). The subjects had been out of high school from one to four years in 1993.

Sample Selection Plan

A three-stage sample selection plan was used to select the subjects: (1) state selection, (2) stratification by community type and gender, and (3) selection of individual subjects. While the sample of five states is too small to constitute a representative sample of all 50 states, care was taken to assure an appropriate mixture of states from geographically diverse regions of the country, from high- and low-density population areas, and from across the spectrum of Gross State Product indicators.

The study sample was further stratified by community type and gender. This stage used two demographic variables to construct a representative sample within each of the five states. First, because community size is a recognized source of differences in educational performance and training (Thorndike, Hagen, & Sattler, 1986; Tyler, 1965), communities in each of the five states were divided into one of three strata according to the U.S. Census Bureau (1990) criteria: large (> 500,000), medium (50,000 – 500,000), and small (< 50,000). Subjects were selected to proportionally represent these three types of communities within each state. Second, since postschool outcome research has often found significant differences by gender, an attempt was made to include a balanced representation of males and females in the sample.

Since the purpose of the NTSSD study was to examine the transition outcomes and current service needs of individuals with severe disabilities, the third stage required the sample to be restricted to individuals of postschool age who met predetermined criteria for severe disabilities. The sample was restricted to potential subjects who had exited the secondary school system within the past four years (1987-91) at the time of the study. This included individuals who exited by graduating, aging-out (at under 22 years of age), or those who dropped out. The severe disability criteria included in the Rehabilitation Act of 1973, as amended, were used to identify potential subjects with a severe disability.

Table 1: Subject Demographic Information

Demographic Variable	n	%
Gender (N=398)		
Female	187	47.0
Male	211	53.0
Urbanicity (N=398)		
Small community (<50,000)	96	24.1
Medium community (50,000 - 500,000)	140	35.2
Large Community (>500,000)	162	40.7
Ethnicity (N=397)		
Asian, Oriental or Pacific Island	3	0.8
African American	74	18.6
Native American	2	0.5
Hispanic	22	5.5
White/Caucasian	287	72.3
Other	9	2.3
Legal Status (N=398)		
Legally competent adult	173	43.5
Parent/relation is guardian/conservator	197	49.6
Non-relative is guardian/conservator	7	1.8
State/county is guardian/conservator	16	4.0
Other	5	1.3
Primary Diagnosis (N=398)		
None	0	0.0
Autism	12	3.0
Blindness	7	1.8
Neurological	30	7.5
Cerebral palsy	34	8.5
Deafness	1	0.3
Epilepsy or seizures	4	1.0
Mental retardation	244	61.3
Physical health problem	3	0.8
Mental illness	4	1.0
Situational mental health	0	0.0
Chemical dependency	1	0.3
Other	58	14.6
***Level of Mental Retardation (N=397)**		
None	59	4.9
Mild (IQ 52-70)	112	28.2
Moderate (IQ 36-51)	107	27.0
Severe (IQ 20-35)	63	15.9
Profound (IQ under 20)	38	9.6
Unknown	18	4.5
Level of Services Needed (N=398)		
Total personal care/intense supervision	49	12.3
Extensive personal care &/or constant super.	46	11.6
Regular personal care &/or close super.	73	18.3
Limited Personal care &/or regular super.	127	31.9
Infrequent or no assistance for daily living	103	25.9

*Includes subjects with mental retardation as either primary or secondary diagnosis.

Subject Demographics

Table 1 summarizes subject demographics and other characteristics. Subjects' ages ranged from 21 to 26 years, with a mean of 23.6 years of age. These young adults had been out of school from approximately 1.75 to 5.0 years, with a mean of 3.4 years. The sample included slightly more males (53%) than females (47%). The majority of the individuals lived in large communities (40.7%), followed by medium sized (35.2%) and small (24.1%) communities. The majority of these young adults with severe disabilities were English speaking (98.5%) and white (72.3%). The remaining sample included 18.6% African-American, 5.5% Hispanic, and 2.3% identified as "Other."

The majority of the sample consisted of individuals with a primary diagnosis of mental retardation (61.3%). The largest portion of the sample was classified as being within either the mild (28.2%) or moderate (27.0%) levels of mental retardation, followed by approximately 15% in the severe and 9.6% in the profound levels of mental retardation. Thus, most of the subjects in the sample were classified as having a severe disability not because of severe mental retardation. Most typically, individuals were identified as having severe disabilities based on several factors, that is, functional limitations, presence of other disabilities, as well as levels of mental retardation. Less than half the sample (43.5%) were legally competent adults. In 49.5% of the cases, the subject's parent or a relation was the guardian or conservator, and in 5.8% of the cases a non-relative or a state or community agency was the guardian or conservator.

Data Collection Instruments

Data collection instruments included a 100-item post-school outcome survey and the *Inventory for Client and Agency Planning (ICAP)* (Bruininks, Hill, Weatherman, & Woodcock, 1986). The postschool outcome survey instrument consisted of 100 questions across 11 sections:

- General Information. Subject identification and general demographic information.
- High School Experiences. Nature of curriculum, extracurricular activities, high school employment experiences, and satisfaction.
- Employment and Daytime Activities. Employment history and characteristics, wages and benefits, education and training programs, and satisfaction.
- Living Arrangements. Where and with whom the individual lives, and satisfaction.
- Family and Friends. Social network, friendships, leisure activities, contact with family members and people in the community, and satisfaction.

- Community Involvement. Participation in individual and group activities, transportation, political activities, and satisfaction.
- Financial Independence. Independence in shopping and banking, and amount and type of supplemental income support sources.
- Personal Choice. Degree of independence or self-determination in making decisions about housing, employment, and leisure activities, and satisfaction.
- Family Needs and Support. Extent to which families receive necessary financial, social, and emotional support. (This section was only completed if the respondent was a biological, adoptive, or foster parent of the subject).
- Social Skills Scale. Degree of social competence exhibited across a variety of social situations. (This section included items that belong in the "personal characteristics" section described below. These items were included in the post-school outcome survey only for logistical reasons – all other personal competence measures were commercially published in their own booklets.)
- Waiting for Services. Availability, access, and use of community services in the areas of general community services, social and recreation activities, educational and vocational training, transportation, housing, employment.

A range of personal characteristics of all subjects were measured by administration of the *Inventory for Client and Agency Planning* (ICAP). In the NTSSD, only the first five sections of the ICAP were completed. These were:

- Descriptive Information. Gender, race, primary language and means of expression, marital status, and legal status.
- Diagnostic Status. Primary and secondary disability diagnoses.
- Functional Limitations and Needed Assistance. Level of mental retardation, status of vision and hearing, frequency of seizures, health limitations, required nursing or medical care, current medications, arm/hand use, mobility limitations, and need for mobility aids.
- Adaptive Behavior. Seventy-seven adaptive behavior items in the broad areas of motor, social/communication, personal living, and community living skills.
- Behavior Problems. Eight different types of internally or externally directed problem behaviors.

Potential subjects were primarily identified from school and agency records and files, and interviews were conducted face-to-face.

■ Results

This section summarizes the major descriptive findings of the study in nine outcome domains: School Experiences/Completion, Employment and Daytime Activities, Living Arrangements, Family and Friends, Community Involvement, Financial Independence, Personal Choice, Family Needs and Support, and Waiting for Services. Table 2 reports selected outcomes. In addition to the descriptive findings discussed here, group comparisons were made on selected variables, examining whether there were significant differences associated with gender, level of mental retardation, years out of school, and geographic location.

School Experiences/Completion

The School Experiences/Completion domain includes variables that focus on the presence and degree of meaningful participation in extracurricular and work activities while in school and the individual's school exit status and degree of satisfaction with school experiences. Results included the following:

- Half of all the individuals in the sample worked for pay during high school, with the majority (approximately 50% to 70%) being employed in jobs as service workers (e.g., food service, laundry, child care, janitor). Clerical and sales (e.g., stock clerks, secretaries, office assistants) (13.1% to 19.2%) and benchwork (e.g., assembling, repairing, fabrication) (8.1% to 12.5%) were the next most frequent types of employment during high school.
- Individuals with severe to profound mental retardation worked for pay less frequently during high school than did individuals with mild to moderate mental retardation.
- Approximately 40% to 50% of the sample participated in some form of athletic or social extracurricular activity during high school. Approximately 16% to 17% of the sample participated in either music, vocational arts, or other extracurricular activities during high school.
- Approximately 80% of the sample successfully obtained a formal school completion award (i.e., diploma or certificate). Over half (56.7%) of the sample graduated with a diploma, while 27% graduated with a certificate. The remaining individuals either dropped out (3.5%) or left school because of age (aged out at 21 years) (12.8%).
- The subjects reported being, or were judged by others to be, generally satisfied with the job, basic skills, and personal living skills training received during high school. Approximately 80% reported being "very satisfied" to "somewhat satisfied" with training in these areas while in school.

Table 2: Select Postschool Outcomes

School Experiences/Completion	n	%
Employment During High School (N=391)		
Worked for pay	197	50.4
Exit Status (N=397)		
Graduated with diploma	225	56.7
Graduated with certificate	107	27.0
Dropped out	14	3.5
Aged out	51	12.8

Living Arrangements	n	%
Living Arrangement (N=392)		
Institution, hospital, or nursing home	17	4.3
Residential placement	82	20.9
Halfway house or apartment training	19	4.9
With parents, foster parents, relatives	227	57.9
By self, with friends, with spouse	47	12.0

Financial Independence and Support	n	%
Economic Independence		
Pays some/all expenses w/ earnings (N=352)	187	53.1
Has savings/checking account (N=387)	263	68.0
Uses accounts independently (N=385)	83	21.6
Shops and buys things by self (N=387)	212	54.8
Monthly Income Support Received		
Medical Assistance (N=375)	217	57.9
SSI (N=384)	285	74.2
SSDI (N=371)	60	16.2
State Supplemental Assistance (N=374)	35	9.4
Food Stamps (N=378)	38	10.1
Other (N=311)	30	9.6

Employment and Daytime Activities	n	%
Education/Training Program (N=391)		
Postsecondary education	16	4.1
Postsecondary vocational	21	5.4
Day activity or training center	129	33.0
Other	34	8.7
None	191	48.8
Employment History		
Worked since high school (N=397)	303	76.3
Experienced unemployment since h.s. (N=313)	142	45.4
Currently working for pay (N=393)	264	66.3
Currently work more than one job (N=297)	29	10.4
Current Daytime Activity (N=263)		
Activities center	23	8.7
Sheltered workshop	91	34.6
Student or job training	14	5.3
Supported employment	45	17.1
Competitive employment	90	34.2
Employment Benefits Received		
Increase in wages (N=248)	89	35.9
Increased job responsibilities (N=258)	105	40.7
Bonus (N=255)	31	12.2
Health coverage/insurance (N=255)	41	16.1
Paid vacation (N=255)	53	20.8
Other (N=209)	36	17.2
Source in Finding Job (N=265)		
Self	14	5.3
Friend	6	2.3
Family member	29	10.9
Counselor	58	21.9
Community agency	150	56.6
Other	8	3.0

Employment and Daytime Activities

The Employment/Daytime Activities domain included employment history and characteristics, wages and benefits, education and training programs, and satisfaction. Findings were as follows:

- Approximately half (48.8%) of the sample was not involved in any postsecondary education or training program. Involvement in day activity or training centers was the most frequent (33%) type of post-high school program participation. Only 9.5% participated in any formal type of postsecondary education or vocational program.
- Involvement in education and training varied by level of mental retardation with individuals without mental retardation being more frequently involved in postsecondary education and individuals with severe to profound mental retardation being more frequently involved in education/training programs in general, and vocational or day activity/training center programs specifically.
- Over three-fourths of the sample (76.3%) worked since leaving high school, with 66.3% of the total sample currently working for pay. Nearly half (45.4%) experienced unemployment since leaving high school, with the average length of unemployment approximately 15 months.
- Approximately one-third (34.2%) of the currently employed subjects were competitively employed. Another 17.1% were working in supported employment. A relatively large number, however, were employed in sheltered workshops (34.6%) and receiving pay for work in day-activity program centers (8.7%).

- Overall, individuals have worked an average of two jobs since leaving high school, been employed 1.5 years in their current job, worked on average 16.25 hours per week, and earned approximately $180 per month.
- Similar to high school work experiences, the majority of the sample was employed doing benchwork (e.g., assembling, repairing, fabrication) (43%), service work (e.g., food service, laundry, janitor) (33.1%), or clerical or sales work (e.g., stock clerks, secretaries, office assistants) (14.4%). Nearly all (90.5%) of those employed in the sample had jobs in one of these three categories. Approximately three-fourths (78.5%) of those employed found employment through the formal sources of a counselor (21.9%) or community service agency (56.6%).
- A total of 20% to 40% of those who worked had received an increase in job responsibilities (40.7%) or wages (35.9%) and a paid vacation (20.8%). Very few received health coverage/insurance (16.1%) through their employer.
- There were no significant differences on any of the critical employment related variables as a function of urbanicity or gender.
- There were a number of significant differences on select employment related variables as a function of level of mental retardation. Individuals with severe to profound mental retardation worked less than those without mental retardation or with mild to moderate mental retardation since leaving high school. Individuals without mental retardation had more jobs since leaving high school than individuals with mental retardation. Average income per month differed as a function of degree of mental retardation; those with severe to profound mental retardation received the lowest income, and individuals without mental retardation received the highest. Individuals without mental retardation or with mild to moderate mental retardation had received more employment benefits than individuals with severe to profound mental retardation.

Living Arrangements

The Living Arrangements domain included where and with whom the individuals lived within the community. Findings were as follows:

- Most of the sample (57.9%) lived with relatives (i.e., parents, foster parents, or other relatives) or lived in a residential group home setting (20.9%). Twelve percent of the individuals currently were living independently of relatives either by themselves or with friends or a spouse. Very few individuals (4.3%) resided in the most restrictive community settings (i.e., institution, hospital, nursing home).
- High levels of satisfaction (93.3% reported being "very" or "somewhat" satisfied) were reported across the sample for current living arrangement.

Family and Friends

The Family and Friends domain included variables that focus on the individual's social network, friendships, and contact with family members and people in the community. Findings included the following:

- Subjects had frequent or very little contact with neighbors and/or with individuals without disabilities in their community. Nearly 50% of the subjects had either daily or weekly contact with neighbors and/or individuals without disabilities. Conversely, approximately 36% of the sample reported "less than monthly" contact with neighbors and/or individuals without disabilities in their community.
- Approximately three-fourths (75.9%) of all subjects reported being (or were judged by others to be) positively accepted in their community. Approximately half (49.9%) of the respondents indicated a "very" positive community response, followed by 26% reporting a "somewhat" positive community response. Only 8.4% reported either a "somewhat" or "very" negative community response.
- The members most frequently reported in a person's social network were those from the person's immediate family ($\underline{M}$ = 3.2 family members) and personal friends ($\underline{M}$ = 2.3 friends), followed by extended family ($\underline{M}$ = 1.4 extended family members) and staff and professionals who served them in program settings ($\underline{M}$ = 1.2 staff/professionals).
- Subjects without mental retardation or with mild to moderate mental retardation were found to have more friends in their social networks than did individuals with severe to profound mental retardation.
- Females reported more extended family members in their social network than did males.
- Approximately two-thirds (64%) of all individuals reported contact with immediate family members on a daily or weekly basis. Approximately 14% reported less than monthly contact with immediate family members.

Community Involvement

The Community Involvement domain included the subject's participation in individual and group activities, transportation within the community, and citizenship activities. Findings included:

- The predominant form of recreation/leisure participation was informal activities around one's home setting, followed next by socialization activities. The most frequent activities were the passive activities of watching television or listening to radio and/or records (97.5%), and sitting around resting (94.4%). Other frequent recreation and leisure activities occurring for over half of the sample were: (a) going shopping (78.2%), (b) reading or looking

at books or magazines (75.2%), (c) going out to eat (74.2%), (d) going to the park or on a walk (61.8%), working on hobbies (59.3%), and visiting with friends (52.7%). Involvement in formally organized and community activities (e.g., attending community events; attending club or organization meetings; going to church; participating in sports) was least common.

- Participation in social, recreation, and leisure activities occurred more frequently for individuals living in medium size communities in comparison to individuals living in small communities. Also, individuals with severe to profound mental retardation participated less frequently in social recreation/leisure activities than did individuals without or with mild to moderate mental retardation.
- Most of the individuals moved about in their community by riding with family members or friends (57.3%), riding in a special van or bus (36.7%), or riding a city bus (25.1%). When someone accompanied the person, it was most frequently the person's biological or foster parents (70.5%), someone the person lived with (54.7%), or a friend (46.2%).
- Subjects with severe to profound mental retardation were much more frequently accompanied by residential staff workers (80.4%) or individuals they lived with (72.3%) than were individuals with mild to moderate mental retardation (29.3% with residential staff; 47.6% with living mates) or individuals without mental retardation (8.6% with residential staff; 50.9% with living mates).
- The degree of community mobility and transaction independence varied by degree of mental retardation (i.e., those without mental retardation were higher than those with mild to moderate, who in turn were higher than those with severe to profound mental retardation).

Financial Independence

The Financial Independence domain reflected independence in shopping and banking, and amount and type of supplemental income support sources. Findings included:

- More than two-thirds (68%) of the individuals had their own savings or checking account, although only 21.6% managed their accounts independently. Approximately half (54.8%) of the individuals shopped or bought things by themselves and paid some or all of their living expenses (53.1%) from their earnings.
- On a general index of economic independence, individuals living in medium size communities displayed greater economic independence than those in small communities.
- The degree of overall economic independence varied by level of mental retardation (i.e., those without mental retardation were higher than those with mild to moderate mental retardation, who in turn were higher than those with severe to profound mental retardation).
- Approximately three-fourths (74.2%) of the individuals received Supplemental Security Income, while slightly over half (57.9%) received Medical Assistance. A portion of the sample also received other forms of federal and state cash benefits: Social Security Disability Income (16.2%), food stamps (10.1%), and state supplemental assistance (9.4%).
- On an index of total number of income support services (e.g. SSI, SSDI, others) received, individuals without mental retardation received less support than individuals with mild to moderate and severe to profound mental retardation. There was no difference in amount of total income support received between the two groups with mental retardation.

Personal Choice

The Personal Choice domain reflected reported independence or self-determination in making decisions about housing, employment, and leisure activities. Key findings included the following:

- The study gathered information concerning individual levels of personal choice and autonomy over everyday life decisions. The individuals in the sample exercised the highest degree of personal choice in the six areas identified in the category Individual Expression. Across study subjects, 40% or more indicated that they decided how to express themselves in areas such as clothing purchases, clothes they wore, recreation and leisure, spending money, and decorating their room. Less than one-third of the sample indicated that they alone exercised control over living arrangements and major programming decisions such as job or day program selection, content of individual program plans, or staff who provide support to them.
- On general indexes of personal choice regarding individual expression and living arrangements, individuals without mental retardation or with mild to moderate mental retardation reported more control than individuals with severe to profound mental retardation. Individuals with mild to moderate mental retardation reported more personal choice than individuals without mental retardation in the areas of individual expression and living arrangements.
- Individuals without mental retardation reported less personal choice in the area of programming when compared to those with mild to moderate or severe to profound mental retardation. Subjects with mild to moderate mental retardation reported more personal choice regarding programming than individuals with moderate to severe mental retardation.

- Individuals living in large communities reported less personal choice regarding individual expression than those living in medium or small communities. Individuals in medium communities reported greater individual expression of personal choice than those in small communities.

Family Needs and Support

The Family Needs and Support domain included the extent to which families received necessary financial, social, and emotional support. (This section was only completed if the respondent was a biological, adoptive, or foster parent of the subject). Noteworthy findings included:

- The social needs of families (e.g., time to be with friends, spouse, others, etc.) was the area of least concern; 40% to 50% of the interviewed family members indicated that things were "very adequate," and an additional 25% to 30% indicated that things were "somewhat adequate."
- Adult day or respite care was the area of greatest family need, with 42.7% of the family members reporting that services in this area were "very inadequate." The two areas that were next in unmet needs (approximately 20% to 25% reporting things were "very inadequate") were the need for more financial planning for the future and help in obtaining community services.
- There were no differences in the social, financial, and social support and service needs of families as a function of gender, time since leaving school, level of mental retardation, or urbanicity.

Waiting for Services

The Waiting for Services domain included the availability, access, and use of community services in the areas of general community services, social and recreation activities, education, vocational training, transportation, housing, and employment. Findings included:

- The most frequently needed, requested, and received services were consistently: (a) help in obtaining community services, (b) assistance in finding and keeping a job, and (c) obtaining public or private transportation.
- Approximately 71.1% of the individuals reported that they needed help in obtaining services, 66.6% needed help accessing public or private transportation, 66.4% needed help finding or keeping a job, and 65.8% needed help obtaining educational or vocational training.
- Approximately 50% to 60% of the individuals had requested and received help in obtaining community services, public or private transportation, and employment.
- Adult programs and services, regardless of the specific area (e.g., social/recreation or educational/vocational training), were consistently perceived and reported to be available for approximately 80% to 90% of the individuals.
- Less than 10% of the sample had been denied service or were waiting for any adult programs or services. The one exception was 16% waiting for different community living or residential placements (average length of waiting period was 32.73 months).
- Across the six adult program and service areas surveyed, the average number of services reported to be available ($M = 5.2$) was larger than the total number of services needed ($M = 3.7$), requested ($M = 3.1$), and received ($M = 2.9$). There were no significant differences in these adult program and service indices as a function of grouping characteristics (i.e., level of mental retardation, gender, number of years since leaving school, urbanicity of community).

■ Discussion

In many ways, the findings and results of this study parallel those of other postschool outcome studies conducted over the past two decades on young adults with severe disabilities. Overall, these findings illustrate a pattern of limited access to postsecondary education programs, employment instability, dependence on others for residence and other forms of support, limited participation in community social events, and significant levels of social isolation among these young adults. Such findings demonstrate the importance and relevance of gathering and reporting comprehensive information on the post-high school experiences of young people with severe disabilities. To better understand the effects of major social investment in special education and transition programs, outcome studies on former special education students must be systematically and routinely undertaken by federal, state, and local agencies. This information must then be shared among school and community services agencies to serve a basis for reaching consensus on the service needs of individuals and promoting more effective coordination in the planning and delivery of these services. By reaching consensus on the needs of individuals with severe disabilities for services, the essential elements of more coherent national, state, and local policy and service delivery practices among agencies can be formulated. This sharing of information on the postschool status of individuals with severe disabilities must also be viewed as a foundation for improving communication, the planning and provision of future programs, and the overall coordination of services. The alternative is to continue to perpetuate unfortunate and costly isolation across agencies in the delivery of services.

This study has also introduced and examined several new domains of community adjustment (i.e., personal choice, family needs and support, access to community services).

The capacity of the individual with severe disabilities to make choices and decisions in everyday situations is viewed as a strong indicator of independence and personal autonomy when living in the community. Overall, individuals in the sample exercised the highest degree of personal choice in several areas. It was found that 40% or more made individual choices in areas such as clothing purchases, clothes they wear, recreation and leisure, spending money, and decorating their room. Less than one-third of the sample, however, indicated that they alone exercised control over their living arrangement and other major programming decisions, such as job or day program selection, content of individual program plans, or staff who provided support to them. While it is difficult to categorize decisions into "more" or "less" important issues in an individual's life, it is evident that major decisions concerning place of residence, with whom one lives, and who provides support to an individual with severe disabilities appear to be made by persons other than the individual with severe disabilities.

This study also examined a range of variables concerning family needs for support. The data gathered and analyzed were obtained directly from the parents or guardians of the subjects in this study. Family support has been broadly defined by some as "whatever it takes to maintain and enhance the family's capability to provide care at home" (Knoll, Covert, Osuch, O'Connor, Agosta, & Blaney, 1990, p. 5). Based on the findings of this study, adult day or respite care appeared to be the area of greatest family need, with 42.7% of the family members reporting that services in this area were "very inadequate." The two areas that were next in unmet needs were assistance with financial planning for the future and help in obtaining community services. Additional research is warranted to identify and document other levels of needed support to families in addressing the needs of their adult son or daughter with a severe disability.

Also investigated and reported in this study was the extent to which young adults with severe disabilities were making needed connections to adult community services upon exit from school. The study examined the needs of respondents for community services in six primary categories (case management, postsecondary education, residential services, job finding and keeping services, recreation services, and transportation). Respondents were asked to indicate their present need for each of these services, whether or not they were currently receiving the services, the availability of these services in their community, whether or not these services have been denied to the individual, and current waiting list status (including the length of time the individual has been on the waiting list). Based on the results of this study, the most frequently needed, requested, and received services were consistently help in obtaining community services, assistance in finding and keeping a job, and help in obtaining public or private transportation. More than two-thirds (71.1%) of the individuals reported that they needed help in obtaining services, accessing public or private transportation, finding or keeping a job, and obtaining needed educational or vocational training programs. Most respondents indicated that they were currently receiving assistance for services needed. Most also indicated that services were available in their local community. Few had been denied services, and few were found to be on waiting lists for any of the identified community services.

These findings seemingly indicate a relatively favorable outlook for individuals with severe disabilities in need of adult community services. To the extent that this finding is not consistent with certain other studies (e.g., Davis, 1987; Hayden, 1992; Sachs, Smull, & Bryan, 1986) that report extensive unmet service needs and long waiting lists for community services, specific features of this study should be reiterated. First, subjects in this sample were relatively recent graduates, many of whom still live with parents (53.8%). These young adults and families may not as yet have actively pursued out-of-home placements or involvement in community services. Further, 25.4% are living in a publicly supported residential settings, through which their needs for transportation, further education and training, recreation, case management, and sometimes employment are often supported. Finally, of course, this study involved graduates in six states. Most comparable studies have either been limited to a single state or have aggregated administrative waiting list data for all states.

Conclusion

This nation seems to be at a critical point. The costs and benefits of special education are being questioned. Policymakers, individuals with disabilities, families, and the general public demand "new" and "better" information as the basis for judging special education's effectiveness and improving its capacity to positively influence the school and adult life experiences and outcomes of individuals with severe disabilities in the United States. Improved methods for organizing and reporting information, in addition to appropriate variable specification and data analysis procedures, are advocated to ensure efficiency in the management and reporting of data. The present study has developed a considerable base of information on the community status and adult life outcomes of individuals with severe disabilities. The study has emphasized the relevance and importance of gathering information on a broad array of community adjustment dimensions in hopes of illustrating the complex nature of community adjustment among young adults with severe disabilities. With a better understanding of the many factors that contribute to quality of life during the years following high school, the prospects will increase for designing more effective public policies, high school programs, adult and community services, and family support systems for persons with severe disabilities and their families.

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A complete summary of the descriptive findings of this study can be found in the report, Descriptive Findings of the National Transition Study of Individuals with Severe Disabilities Leaving School (Johnson, McGrew, Bloomberg, Lin & Bruininks, 1995) available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. Telephone: (612) 624-4512.

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